Women's Receptivity to Testing for a Genetic Susceptibility to Breast Cancer

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ABSTRACT

Four hundred eighty-four patients undergoing mammography and 498 patients visiting their obstetrician-gynecologist were asked whether they would take a breast cancer 1 (BRCA1) test to detect a genetic susceptibility to breast cancer. More than 90% in both groups said they would take the test. Women were more likely to accept if they were regularly having breast examinations by a physician, believed that mammography effectively detects early breast cancer, and believed that early breast cancer is curable. If shown to have inherited a susceptibility, many reported that they would be very anxious, would want the test repeated, would examine their breasts more often than monthly, and would want mammography more often than yearly. Many also reported that they would recommend testing to relatives. (*Am J Public Health.* 1995;85: 1133–1135)

Introduction

The breast cancer 1 (BRCA1) gene[1,2] has recently been cloned and sequenced.[3,4] Many BRCA1 mutations have been characterized in families previously shown to have a chromosome 17q-linked susceptibility to breast cancer.[3–7] The large size of BRCA1, the large number of mutations, the need to distinguish polymorphisms from pathogenic mutations, and the existence of other loci for hereditary breast cancer susceptibility (e.g., BRCA2)[8] will complicate testing. Nevertheless, because of the salience of the breast cancer threat, these technical problems are likely to be solved, raising the following question: Will women choose to have a test to identify BRCA1 mutations if such a test becomes available? We conducted a survey to determine women's receptivity to this type of testing.

Methods

The subjects surveyed were awaiting medical services in one of two settings, a radiologic practice specializing in the diagnosis of breast disease or a general obstetrics/gynecology group practice. One of the investigators, a female physician who was not a member of either practice, approached patients waiting to be seen and asked them to complete a questionnaire. The questions were preceded by the following statement: "A blood test identifying certain women as having a gene associated with a high risk of developing breast cancer in her lifetime is likely to be available in the next few years. In order to decide whether women will use such a test, we would appreciate your answering the following questions." Questions assessing attitudes involved five-point (Likert) response scales (e.g., strongly disagree, disagree somewhat, neither agree nor disagree, agree somewhat, or strongly agree).

Results

The rate of participation was very high; 95% of the obstetrics/gynecology patients and 98% of the mammography patients agreed to participate. Questionnaires were completed by 484 mammography patients, 343 gynecology patients, and 155 obstetrical patients.

Of the women surveyed, 31.4% of the mammography patients and 22.5% of the obstetrics/gynecology patients had at least one affected first- or second-degree relative. Patients having mammography were significantly more likely than patients visiting their obstetrician-gynecologist to have an affected first-degree relative (83% vs 29%; $P < .001$ by chi-square test).

Patient responses to the offer of testing are summarized in Table 1. Reasons given for accepting the test included "to take extra precautions if the risk were high" (59%) and "for reassurance that the risk was low" (38%). Predictors of test acceptance are given in Table 2. Women declining the test (5.9% of the total) reported that they were content with what they were currently doing about the risk of breast cancer, did not like to have their blood drawn, or were made too anxious by thinking about taking the test.

Women were willing to pay more for the test if they were older ($P < .001$), if they were having mammography regularly ($P < .001$), if they were very concerned about getting breast cancer ($P < .001$), if they believed that mammography effectively detects early breast cancer ($P < .001$), if they thought their own risk was high ($P < .003$), and if they believed that early breast cancer is curable ($P < .03$) (the preceding significance levels were obtained through correlations). Also, they were willing to pay more if they were not pregnant ($P < .003$ by t test) or

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TABLE 1—Patients' Responses to a Prospective Offer of Testing for Genetic Susceptibility to Breast Cancer

Response	Mammography Patients (n = 484), %	Obstetrics/Gynecology Patients (n = 498), %
Would accept test if free	96	93
Would be willing to pay more than $25 for test	68	53
Want to be notified when test is available	80	56
If positive, would recommend testing to a relative	61	55

TABLE 2—Predictors of Patients' Acceptance of an Offer of Test for Genetic Susceptibility to Breast Cancer

Predictor	Women Accepting Test Offer (n = 903), %	Women Declining Test Offer (n = 53), %	P[a]
Believing that early breast cancer is curable	93	74	<.001
Having breasts regularly examined by a physician	95	79	<.001
Concerned about getting breast cancer	93	82	.001
Believing that mammography effectively detects early breast cancer	93	86	<.035
Having mammography regularly	95	89	<.050

[a]By chi-square test.

if their mother had had breast cancer ($P < .005$ by t test). Women whose reason for accepting the test was to take extra precautions in case of a positive result were willing to pay more than women whose primary reason for accepting the test was to be reassured that their risk was low ($P < .002$).

Of the women who would accept the test, many said that if the test showed that they had inherited a susceptibility to breast cancer, they would be very anxious (44%) and want the test repeated (56%). Nevertheless, they would examine their breasts more often than monthly (69%), want a mammogram more often than yearly (50%), and recommend testing to a female blood relative (62%). On the other hand, if the test showed that they had not inherited the susceptibility, they would worry less about breast cancer (86%) but would continue to examine their breasts (75%), to have their physician examine their breasts (86%), and to have mammography regularly (76%).

Sixty-eight percent of women wanted to be notified when the test became available; this percentage was higher for the women identified by having mammography (80%) than for those having gynecological or obstetrical visits (56%). Women in the groups that were willing to pay more for the test were also more likely to want to be notified when the test became available. For example, 85% of women with a first-degree affected relative wanted to be notified, in comparison with 65% of those without a first-degree affected relative ($P < .0001$ by chi-square test). Women were also more likely to want to be notified if they thought that early breast cancer was curable (69% vs 57%; $P < .02$) or if they had a maternal aunt with breast cancer (83% vs 66%; $P < .005$). Having only paternal or second-degree maternal affected relatives was not associated with test acceptance.

Discussion

In both groups, the percentage of women stating that they would accept the test was remarkably high, considering the threatening nature of a positive result. However, this response should be interpreted cautiously since (1) some women who may feel they should want the information might not accept the test when actually offered[9] and (2) the context of the offer did not permit a full explanation of the significance of test results (e.g., that a negative result per se might not constitute grounds for reassurance).

Women in the mammography group generally regarded testing more positively than did women in the obstetrics/gynecology group. However, the two groups differed not only in the medical setting in which they were approached but in other characteristics, such as age (means of 53.8 and 37.1 years for the mammography and obstetrics/gynecology groups, respectively), percentage minority (10% and 16%, equally Asian and African American), and percentage pregnant (0% and 30%). The older age of the mammography group may have contributed to the higher incidence of breast cancer among relatives.

Women who would accept the test indicated that, if they tested positive, they would undertake increased surveillance, including regular mammography. Some professionals might object to regular mammography in younger women because mammography for women less than 50 years of age generally has not been shown to improve survival from breast cancer.[10] However, abnormal mammograms have recently been reported to have a higher positive predictive value (i.e., a higher proportion of women who have an abnormal mammogram having breast cancer on biopsy) for women 40 to 49 years of age with a first-degree relative with breast cancer than for unselected women 50 to 59 years of age.[11]

The actual offer of such a test should be preceded by careful patient selection and pretest education of the patient about the significance of test results.[12–14] For the present, only patients with a family history of breast cancer should be offered testing. A relative who has already developed breast cancer should be tested first. If the relative has no BRCA1 mutation, then testing of the counselee is not indicated. If the relative has a BRCA1 mutation shown in other families to cosegregate with breast cancer and the counselee shares it, a high risk is confirmed; however, the counselee must be warned before testing that no intervention (even prophylactic mastectomy) has been shown to unconditionally guarantee survival. If the relative has a mutation not previously described, other affected and older unaffected mem-

bers of the counselee's family must be tested and this mutation shown to cosegregate with breast cancer before the counselee is offered testing. Only if the relative has a mutation known to be pathogenic and the counselee lacks that mutation is some measure of reassurance justified, but the counselee must understand that she can still develop breast cancer due to an inherited mutation in a gene other than BRCA1 or breast cancer of sporadic origin.

Thus, the acceptance rate among women who receive the preceding information may be lower than the rate among women in this survey. Extensive education of providers, as well as potential testees, will be necessary to maximize the benefits and minimize the burdens of BRCA1 testing. □

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Mortality Rates among 15- to 44-Year-Old Women in Boston: Looking beyond Reproductive Status

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ABSTRACT

Mortality rates were examined for Boston women, aged 15 to 44, from 1980 to 1989. There were 1234 deaths, with a rate of 787.8/100 000 for the decade. Leading causes were cancer, accidents, heart disease, homicide, suicide, and chronic liver disease. After age adjustment, African-American women in this age group were 2.3 times more likely to die than White women. Deaths at least partly attributable to smoking and alcohol amounted to 29.8% and 31.9%, respectively. Mortality was found to be related more directly to the general well-being of young women than to their reproductive status, and many deaths were preventable. African-American/White disparities were most likely linked to social factors. These findings suggest that health needs of reproductive-age women transcend reproductive health and require comprehensive interventions. (*Am J Public Health.* 1995;85:1135–1138)

Introduction

Researchers and policymakers have recently begun to focus on women's health. However, concern has been directed at the problems of older women, with little attention given to the overall health needs of women aged 15 to 44 years. For example, the Women's Health Initiative of the National Institutes of Health has concentrated on postmenopausal conditions such as cardiovascular disease and osteoporosis.[1] Concern for younger women, by contrast, has been directed to optimizing reproductive outcomes. In 1992, all states provided pregnancy-related services for women whose incomes were below 133% of the federal poverty level[2]; only Hawaii has attempted to extend public health care benefits to all women, regardless of pregnancy status. For the privately insured, 95% of employee-sponsored insurance plans pay for prenatal services, but fewer than one third of conventional insurers pay for routine, preventive care for nonpregnant women.[3]

The current neglect of the general health of reproductive-age women coincides with new threats to their well-being. In the last 10 years, the rates of traffic fatalities,[4] smoking-related diseases,[5] and human immunodeficiency virus (HIV)[6]

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